

An Ethnography of Sickle Cell Disease

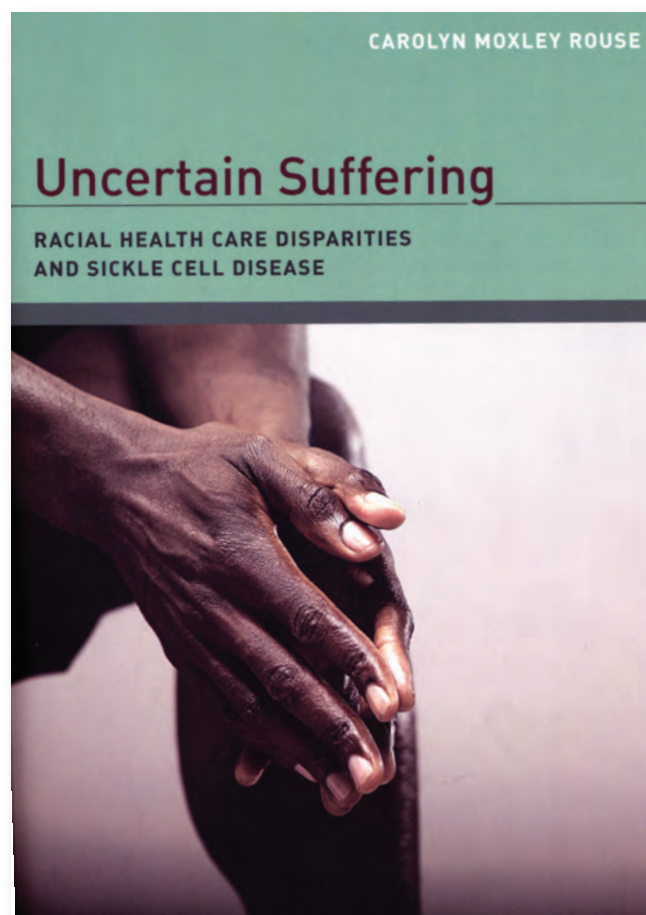
Carolyn Moxley Rouse '87 *Uncertain Suffering: Racial Health Care Disparities and Sickle Cell Disease*, University of California Press, 2009

With good reason, one should hesitate before describing an ethnography about those with an incurable disease—and the broken health care system that attempts to treat them—as “wonderful,” but such is the elegant scholarship of Carolyn Moxley Rouse on the topic of sickle cell, a disease that disproportionately affects African Americans in the United States.

Uncertain Suffering is an ethnography—the study of a people. Most of us assume that “a people” are bound together by geographic space or tradition, filial or religious ties. The people of Rouse’s study are bound by their association with sickle cell disease (SCD), whether they have the disease, are related to persons that have it, or treat it. In this study of SCD culture, we learn how people with the disease cope with pain, how they are treated by others, how and why pain is occasionally uncoupled from suffering, what specifically is and is not working for them in the health care system, and how a vulnerable but unpitied group outside of hospital walls is treated when they meet up with the supposedly objective and evidence-based protocols to treat their disease found within hospital walls.

Rouse—like the best students I have had at Swarthmore—attempts to accomplish two dozen things at once. She describes the disease, the social location of those who suffer from it, the responses from the professionals who treat them, and how treatment differs when the racial makeup of a treatment center’s professional staff differs. She uses social theory to interrogate taken-for-granted medical concepts such as “evidence-based” and “objective;” offers rich observations and nuanced quotations from her interviewees; and posits recommendations for social philosophers, the federal government, and the SCD community.

Precisely because Rouse accomplishes so much in this book, it will have its detractors. Let me anticipate their complaints. The book often reads like a weighty conversation in which quite a bit of background knowledge is assumed. As someone who’s done the background reading, it was a pleasure. That said, I want *Uncertain Suffering* to be read by policy wonks, physicians, nurses, and nonprofit directors—and it’s pretty dense for a wide audience. Still, it’s crucial



reading for anyone in the helping professions.

Rouse also takes for granted the intelligence, humor, and insight of the mostly poor, all black, mostly adolescent patients that she got to know during the course of this study. By taking their point of view as a starting point, she treats those at the margins as if they were at the center—reversing, upending, and overturning the paradigms in which we’ve been trained.

Rouse lays out her thesis early, and some detractors will assume that she reached her conclusion before she began the research. To the contrary, she brings readers along on her journey, revealing the limitations or errors of her hypotheses along the way. She writes, for example: “In spite of a growing consensus that began in the 1980s that pain, particularly for cancer, should be treated aggressively, almost 30 years later sickle cell patients remain the exception.... Physician discretion still plays a key role in patient access to medications.” Her outrage is clear. But three pages later, she writes, “After switching

research field sites, I was forced to challenge my rather two-dimensional perspective....”

Rouse comes to learn, she says, that helping patients manage pain is the subject of much disagreement. SCD centers that have majority black staffs have a different approach than those with majority white staffs, but the differing approaches do not correlate with her initial expectations. Increasing quality of life is not necessarily a conclusion that can be reached via statistical analysis—and quality of life, rather than pain eradication only, she learns, informs the approaches of SCD clinics with majority black professional staffs.

For all of us struggling to understand how discourses of rationality, fairness, and compassion respectively could lead us to the Iraq War, the response to Hurricane Katrina, or the health care reform debacle, Rouse offers some complicated answers. She reminds us that too often we live with competing contradictions while simultaneously forfeiting power to professionals whose prose confounds us. And when we’re the professionals, we’ve often taken our own professional baptism without remaining suspicious of our socialization and without continuing to question the art and science into which we’ve been socialized.

—Sarah Willie-LeBreton,
associate professor of sociology and anthropology